



Infant Feeding Tips and Support for HSD/EDS Parents

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This handout is to support positional, sensory, tissue, and other issues that are common for parents with hypermobility, EDS (Ehlers Danlos Syndrome), POTS (Postural Orthostatic Tachycardia Syndrome) and/or MCAS (Mast Cell Activation Syndrome), which are comorbid syndromes, meaning they tend to occur together. Sometimes breast or bodyfeeding is not accessible or chosen, but having EDS is not inherently prohibitive. Feeding is feeding, whether your path is nursing, pumping, bottle feeding with human milk or formula, or a combination (which is usually the case). Each variation can present issues for someone with a connective tissue disorder.



Chronic Pain or Illness Can Cause Issues Perceiving & Troubleshooting Pain

- Often people with EDS or any chronic illness unnecessarily resign themselves to pain while holding and/or feeding an infant. Chronic pain or illness does not mean that carrying, holding, or breastfeeding/pumping will be painful. People with chronic pain can disassociate from paying attention to pain as a matter of survival, not finding relief, they come to expect things to be painful and accept it as their reality.
- One hurdle can be relying on standard support that is not informed about the issues with EDS tissues. Seeking support can be more daunting for Zebras because of prior trauma with the difficulty of being diagnosed with EDS plus having issues finding effectively supportive medical care.
- Remember that pain while feeding, lactating, or nursing is an indication that something should be adjusted. Inflammation, painful let-downs or latches can often be relieved with skillful, informed support. A latch should not be painful or even uncomfortable after the first week or so.



Tissue Fragility and MCAS (Mast Cell Activation Syndrome)

Nursing puts stress on nipple tissue in the first weeks. Because Zebras can have more fragile tissues, they respond poorly to tissue inflammation, and may heal slowly. In the first week or so, tissues are remodeling when the mechanical force of the vacuum of the infant nursing causes microfissures. The healing of these inflamed microfissures increases the amount of vessels and collagen in the area to help develop the tissue for nursing.

This remodeling of tissue can be complicated by a number of factors for someone with EDS:

- Cytokines and histamines can set off a mast cell (over)reaction that contributes to more inflammation instead of starting the process of healing.
- Tissue fragility can create more damage than is expected.
- Tissue remodeling can be impaired either in strength or time to heal.
- Recent research states that the previous standard lactation consultant recommendation for positioning (shaping the breast with cross-cradle hold) is associated with a dramatic increase in nipple pain.

To reduce the risk of cracks and to help remodeling of tissue

- Prepare ahead of time to make sure your MCAS medications are safe for nursing and maintain that protocol.
- Keeping the nipple very dry, free from pads or bras that retain moisture.
- Allow for baby-led latching, with low chin at areola placement, to allow the nipple to extend deep to the soft palate of the infant.
- Avoid the “squeezing breast and placing infant head” latch placement (shown to the left).



Shaping the breast with your hand and manipulating infant head is now understood to contribute to an increase in nipple pain

Other MCAS Considerations

If you have MCAS, it is possible your child could have similar issues. Look for the following:

- Diarrhea after the parent eats certain foods
- Having a harder time than expected to find a formula that the infant tolerates and thrives on. Research things like the source for DHA in the formula in case of seaweed or fish sensitivities in the family.
- Projectile spitting up can also be an indicator.
- Contact with detergent or soap causing rashes, or rashes or welts of unknown origin.



POTS (Postural Orthostatic Tachycardia Syndrome) Considerations

- When you are lactating, it is important to dramatically increase the fluids you already drink for POTS. Producing milk requires extra fluid as well.
- If you are prone to lightheadedness or fainting, consider setting your infant aside and standing up on your own after sitting during any type of feeding session. Once you feel stable, you can reach down to collect the baby either by hand, or bring baby up with an adaptive carrier or seat they have been placed in. If you have a changing station or seat on a table next to you, you can place the baby there as you stand up to avoid having to lean down and risk any further lightheadedness.

Painful Let-down, Vasospasms, Raynaud's Syndrome

Pain during let-down early in breastfeeding is caused by vasospasms, which are spasmodic contractions of the smooth muscle lining the walls of the small arteries and arterioles. It is not yet understood why vasospasms in the breasts are common in the first few months of breastfeeding, other than possibly inflammation impacting the autonomic response.

Vasospasms, and the chronic manifestation of them known as Raynaud's Syndrome, often coexist in people with EDS. Vasospasms are thought to be an over-reaction of the sympathetic nervous system, also known as dysautonomia (POTS is also a type of dysautonomia).

Regulation of vasospasms is just beginning to be studied, warmth and stabilization of MCAS and dysautonomia issues are the recommendations currently to try to moderate frequency. Ask your clinician about being prescribed Nifedipine for frequent, painful vasospasms that cannot be relieved by the standard practices.



Supplemental Nursing System (SNS)



Seated in bouncy or high chair and bottle fed



Family member feeding



Newborns and older babies can be spoon fed milk/formula if there are issues with body or bottle feeding

Sensory Issues and Nursing

For parents that have sensory issues, or are neurodivergent/neuro-atypical, understanding reasons for fidgeting and learning about latch instincts and body alignment can be a good start to help reduce pulling, biting, or fidgeting that might overstimulate the parent.

- Set up in a place to eat that does not have many distractions, don't wait too late to feed, and provide soothing sounds or a quiet environment. (This holds true throughout mealtime during all of childhood.)
- Babies may skin pinch or twiddle the other nipple, this can be an indication that the milk flow or latch is not satisfactory. If there does not seem to be a problem, you can try giving them a fidget toy.
- People with chronic illnesses tend to put up with something that is painful. You can break a painful latch pressing a pinkie into the side of their mouth, and then use the troubleshooting tips to reset in a way that is more comfortable for you.
- A fidgety or fussy baby is sometimes trying to communicate an issue to you. Babies can communicate with sign language as early as 6 months, start signing to them early in infancy so they can tell you what they need. There are many resources for infant signing.
- Babies with sensory issues or autism can easily be frustrated with scheduled breaks to burp or switch sides. Instead pay attention to baby's signals that they may need to burp or they are done, like turning their torso side to side, bouncing, or popping off the nipple.
- Have alternatives to nursing if you are feeling touched out, like a cloth barrier between you and baby or any of the alternatives illustrated on the left.
- Babies with sensory issues or differing mouth shapes (like a deep roof of mouth or wide gape) can take a bit more consideration when figuring out the size and shape of nipples for bottles.

A happy parent is important, so don't feel self-conscious with any of these work-arounds in order to maintain boundaries for yourself. Demonstrating good boundary setting early in life sets up the child having a great skillset for maintaining their own boundaries and honoring others'.



The Basics of Breastfeeding and EDS Considerations

Latching

Fragile tissues or blood vessels can be an issue when considering bodyfeeding, whether it is by nursing or pumping. A well considered infant latch or pump flange size* can help prevent pain, tearing or bruising.

- Position the child so their chin is just under the areola, the bottom lip just on it.
- Wait for a wide gape (open mouth) as the child goes in for the latch.
- These two things are setting up for the nipple to be placed fully/deeply in and up along the roof of the mouth. This positioning can take practice for anyone, but an EDS child can have a deeper roof of the mouth so a placement that is good for both an EDS parent and/or an EDS child can take some patience & support.
- Practice when you and your baby are calm and relaxed, not as a last ditch effort on a frustrating day.

**Consult a specialized lactation consultant who has an understanding about fragile and different textured tissues for type of pump and flange size.*



Tummy Crawl Golden Hour

During the skin-to-skin tummy crawl immediately after birth, notice they are lifting their head up to look for their parent's face and nipples. This moment is the highest peak of oxytocin to help bond and avoid postpartum depression.

Baby's First Latch

To the left is the real beginning of the first latch for this baby. I took this picture as this baby found the nipple for the first time after its tummy crawl. Notice its chin placed below the nipple, the head tipped back--just like yours does when you drink--the mouth wide open in preparation to take the whole nipple deep into its mouth. You can just barely see the tongue sticking out to assist the latch.

Torso Alignment and Contact

Look for alignment of the spine with ear, shoulder and hips all in a line and in contact with your body.



4 Ways to Troubleshoot Basic Issues

- Check that their torso is lined up, head is a bit tipped back, and chin is just below the nipple first to trigger the baby's mouth to gape open to take as much nipple in the mouth as possible.
- Are you tummy to tummy? Bare skin to skin can help.
- Bring baby to the breast, don't hunch over taking breast down to baby.
- Are their hands free to knead to stimulate milk production? (Think of cats paws when cuddling and purring.)

To understand why this alignment is so important take sip of a drink into your mouth, turn your head to the side, drop your chin, and try to swallow. Any variation of how far you are turned and dropped ranges from uncomfortable to painful. You normally drink by slightly tipping your head up and not turned... your baby wants the same whether nursing or drinking from a bottle or other equipment.

The Rule of Threes

Expect to have issues with body feeding on the 3rd day, 3rd week, and then approx every 3 months.

Of course this is very simplistic, but regular growth patterns and hormone changes will disrupt routines. You may need patience and problem solving skills during these transitions as new routines are established.



Accessible Nursing and Feeding Positions That Support Both the Parent and Baby

- Cross body, tummy to tummy, reclined positions are good for strengthening baby's neck and back muscles. It may seem like infants are too weak to lift their heads in this position, but they can surprise you with their strength. It can even help the neck stability of infants suspected of having EDS.
- Firmer support cushions, like those specifically for nursing support or wedge pillows, are safer than soft bed pillows for supporting the infant. Do pay attention to what tools work best for the baby's body alignment and joints.
- Continue using your adaptive devices like braces and sports tape in addition to these supported positions. If you use massage pillows, TENS units, or warm or cool packs daily for pain management, you can practice rolling those into your sedentary time during feeding sessions.



Reclined Tummy to Tummy



Reclined/Mostly Flat Cross Body



Cross Body Slight Recline Leg Prop Supported Hold use support under knees or sit in a recliner



Both Baby and Parent Sidelying Neck and body stabilized with pillows for parent



Reclined Cross Body



Pillows/Foam Wedges Supporting Baby



Furniture Supported Sitting Up



Reclined Tummy to Tummy with Wrap Supporting Arm and Baby



Baby Wrap Supported Wrap is wide at shoulders for ease on EDS joints



Football Hold Arm Supported by Furniture or Pillow



Upright Baby and Parent



Kangaroo Shirts w/ pouches or wraps



Rooting

Nuzzling or rooting around on anyone, and chewing on fists are hunger cues. Learning to pay attention and respond to these cues helps avoid frustration for both you and your baby, and tells your baby that you are reliable at responding to their needs.

Frequency and Duration

- In the first few months of life, feeding is on demand. This basically means you are responding to hunger cues like certain sounds and rooting.
- This can be as often as 1 1/2 hours to 3 hours and are rarely consistent and can be grouped close together/"cluster feeding".
- An EDS infant may have differing gut motility so pay attention to their cues to feed and whether they are gaining weight (it is considered normal to lose a bit in the first week or two, you may hear the phrase "back up to birth weight")
- Early in infancy 4 hours is usually considered too long between feedings.
- A young infant feeding can take around 20 minutes for each breast, as they get older that time can be reduced by half. If bottle feeding, the duration of the feed might be shorter due to the faster flow of milk/formula.



Digestion/Gastrointestinal Issues

- Often people with EDS have weaker sphincters that may not prevent food coming back up the throat, or have slow gut motility so they need a longer time to digest their food. Staying upright for around 30 minutes after feeding will allow liquid to digest and move past the stomach.
- Feeding them in a more upright position helps the milk pool in the mouth to mix with saliva, the first stage of digestion.
- The flow of liquid and the shape of a bottle nipple may also need to be adjusted to reduce the flow of milk/formula.
- All these practices may also be helpful to a child that is "colicky" or has reflux.



Tongue Tie and Tethered Cord

The frenulum is connected to the fascia that runs down to the base of the spine, if there is suspected tethered cord because of occult spina bifida signs, somewhat common for people with EDS, and a painful latch, have the baby assessed for tongue tie.

Eye & Skin Contact Creates Endorphins & Oxytocin for Parent & Child

Oxytocin that comes with close contact can be a free mood elevator! People with EDS are more prone to depression and anxiety due to a number of factors, so a steady flow of oxytocin is a way to reduce your chance of postpartum depression. Plus watching their body language is treating your child like a person that has information to communicate and helps be aware of any frustration before it builds.



Medications While Lactating

Often people with EDS take supplements, prescriptions, and over the counter medications for pain or other issues. Luckily the majority of over the counter pain medications are safe, but check in before birth with your doctors, pain specialist, and pediatrician. This gives you a chance to make a plan for anything that is contraindicated when lactating, and any issues you may have with changes to your medications or supplements.



Resources used to create the handout and for you to find out more

Because this handout only touches on the support you might need

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<https://www.youtube.com/@nourishedyoung>

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Research for the people, by the people!



Education

- University of Houston, History B. A.
- Birth Advocacy Doula Training/BADT- Full Spectrum Doula
- Evidence Based Birth® Childbirth Instructor
- Birth Advocacy Doula Training/BADT- Childbirth Education
- Trans Birth for Birthworkers- Trystan Angel Reese
- Ehlers Danlos Syndrome Society ECHO Programs- Nurses, Clinicians, Allied Health Professionals, Pediatricians, and Genetics and Genomics
- Birth Advocacy Doula Training/BADT- Birth and Disability Workshop



Author Positionality I am a birthwork professional and patient advocate specializing in supporting disabled people. I attend the Ehlers-Danlos Society ECHOs monthly. I have EDS (diagnosed at 45 years old) and breastfed, pumped and bottle fed one infant. I am a white, lower middle class woman. I co-conducted an Ehlers-Danlos Syndrome/Hypermobility/Connective Tissue Disorder: Reproductive Health Survey with Erica Evans, a fertility counselor who also has EDS, in 2021/22 to inform our professional practice.



Audience Focus The intended audience for this document is people with various forms of connective tissue disorders and/or hypermobility, although most of the information can be helpful for both able-bodied and people with other types of disabilities. It does not address every issue you may experience, nor can any other support document.

Images Permissions All images are from Canva except for the two in the Golden Hour/Baby's First Latch window, which are by the author and are used by permission from the client.

Inclusive Language and Images Statement This document switches between the terms "nursing", "breastfeeding", "bodyfeeding" and "lactation" to be inclusive of language that various people use for the act of feeding their young with milk from their mammary glands. Images are inclusive of gender, race, and ability within what was available via Canva images that demonstrate positioning and support accessible to those with hypermobility and joint-instability. My wish is to collect more images of people with visible disabilities to include in this document, but there are no images in Canva of someone holding a baby in a wheelchair or other adaptive devices.